

EDITORIALS

Depression in Caregivers of Patients with Dementia

A Greater Role for Physicians

What is it like, day after day, year after year, to be the family caregiver of a person with dementia? Here is what one woman, who cared for both her mother and her aunt with dementia, said:

Mother was pacing at night, constantly wringing her hands, hoarding things, and jumping at noises. She was irrational, incoherent, having delusions about being watched, and she started to have difficulty swallowing...I had little to no time for business clients, was becoming short tempered, and had developed a grave medical problem that needed attention...Caregiving is enormously stressful. Mine was compounded by excessive paperwork, widespread misinformation...and huge city bureaucracies...Most distressing was hearing health care workers and city employees refer to the disease as just memory loss that requires more patience. It is so much more than that...¹

Another daughter, whose mother had survived the Holocaust and believed that her medical problems were caused by spells created by her former tormentors, said:

Fortunately, I have some exceptionally close friends, but even they became a burden...When my friends called at the end of the day I literally couldn't speak to them because I had no saliva left in my mouth. I started resenting their calls, and finally told them there is no point in reiterating what she does every day because it doesn't change...Looking back, it would have helped if the doctors had talked to me about what it was going to be like for me as a caregiver.²

According to the Alzheimer's Association, over 70% of the 4 million Americans with dementia are cared for at home by family caregivers. The study by Covinsky et al. in this issue of the *Journal of General Internal Medicine* extends our knowledge of the extent and complexity of depression among dementia caregivers. The authors have analyzed a range of characteristics of a large, geographically and ethnically diverse population of caregivers and patients with moderate or advanced dementia.³ Over a third of the more than 5,000 caregivers in the study reported six or more symptoms of depression.

Some of the independent factors that predicted caregiver depression were younger age, being white or Hispanic, having less education, low income, and spending 40 to 79 hours a week caregiving. Daughters were more vulnerable to depression than sons, but both male and female spouses had high levels of depression. Caregivers of patients who exhibited angry or aggressive behavior and those who needed assistance in more activities of daily living (ADLs) were more likely to be depressed than those caring for those without these characteristics.

As the authors point out, we need more information about the impact of ethnicity on caregiver depression. In

addition to the factors mentioned in the report, Hispanic caregivers, who had the highest rates of depression, may encounter language barriers in dealing with the health care system. Even if the caregiver speaks English well, it is likely that the elderly patient does not. Interactions with non-Spanish-speaking health care workers can be perceived as disrespectful to the older person.

One factor that was not considered in this report was the length of time caregivers had been on the job. Does depression deepen over time, or do some caregivers adapt to chronic stress and find ways to compensate for the strain? Another factor that may contribute to caregiver depression is the frustration of dealing with a complex and unresponsive health care system. Both quotes from caregivers at the beginning of this editorial point to failures of the health care system to prepare and support them.

Covinsky et al. conclude, appropriately, that "efforts to identify and treat caregiver depression will need to be multidisciplinary, consider the cultural context of the patient and caregiver, and focus on multiple risk factors simultaneously." Whose responsibility is it to identify and treat caregivers? Certainly the caregiver's own physician is the first line of defense. But, in today's pressured health care environment, will a physician be able to take the time to inquire into the caregiver's home life when the presenting complaint is a "bad back," insomnia, or other physical ailment? At the very least, physicians should be aware of the potentially detrimental effects of caregiving and ask about it. Sometimes all a patient wants to hear is that her doctor understands what she is going through. Other times, of course, prompt action and/or referral are essential.

Physicians who care for a patient with dementia, but are not the caregiver's physician, have responsibilities as well. The quality of care for their patient depends on a caregiver who is able to function and has adequate support from formal services and community resources. Caregivers frequently say that they want better information from their relative's physician about the disease, what to expect, and how to handle its manifestations.

Even if caregiver depression is recognized, what then? Cultural differences may affect caregivers' attitudes about treatment. In a study of primary care patients, Cooper et al. found that acceptance of antidepressant medication was significantly lower among African-American and Hispanic patients than among whites, while more than 90% of African Americans believed that "prayer can heal depression."⁴

Physicians should not feel that they are alone in providing assistance. While by no means adequate, there are many more resources now than in the past—such as adult day care, home care, psychological counseling, support groups, and legal and financial planning services. The federally funded National Family Caregiver Support Program provides respite, information and referral, and counseling through local Agencies on Aging.⁵ The Administration on Aging also funded a project called “Making the Link,” which is specifically designed to help physicians and their staff identify and refer caregivers for services.⁶ The American Medical Association’s Caregiver Self-Assessment Tool is a simple checklist that can begin a conversation about depression.⁷ The Alzheimer’s Association is an excellent resource,⁸ as are numerous Internet sites offering information and online and in-person support groups.

No intervention can erase caregivers’ sadness and loss when their family member suffers from dementia. But by 1) asking about caregiving; 2) treating depression or making appropriate referrals; and 3) providing information about community resources, physicians can play a key role in guiding caregivers away from the shoals of crippling depression.

—**Carol Levine**, *United Hospital Fund, New York, NY.*

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